

DOCUMENT RESUME

ED 236 877

EC 160 898

AUTHOR Miles, M.
 TITLE Deafness in Rural Asia.
 PUB DATE Jan 83
 NOTE 7p.; Document may not reproduce well.
 PUB TYPE Viewpoints (120)
 EDRS PRICE MF01/PC01 Plus Postage.
 DESCRIPTORS Attitude Change; *Deafness; *Foreign Countries;
 *Incidence; *Intervention; Organizations (Groups);
 *Prevention; *Rural Areas
 IDENTIFIERS *Asia

ABSTRACT

The status of services for deaf people in rural Asia is examined. The lack of prevalence statistics is noted as is the concomitant problem of parents, families, and impaired individuals concealing the impairment. Attempted solutions according to the western model are seen to include prevention, early detection and intervention, specialized education and steps to encourage the integration of hearing impaired people into the community's normal life. Political opposition to prevention is cited and the unavailability of intervention services is seen as a major obstacle. Possible improvements are considered in three areas: promoting accurate information and positive attitudes on rehabilitation, encouraging parents and advocates to band together in associations for increased influence, and producing appropriate technology for inexpensive, desirable, and easily maintained hearing aids. (CL)

 * Reproductions supplied by EDRS are the best that can be made *
 * from the original document. *

DEAFNESS IN RURAL ASIA

Invisible Problem

1975
ED236877

Deafness is largely an invisible problem in rural Asia. Governments have no reliable prevalence statistics, usually no hearing impairment figures at all, so the problem does not officially exist. (Even in Britain statistics are admitted to be very imperfect. (D.H.S.S.)). Rural medical personnel have neither audiometric equipment nor training in reliable methods of clinical detection and assessment. The impairment is not visually evident, so it often passes undetected in rural health centres. In the family, health expectations are low: a mild or moderate impairment does not appear significant where serious illness and death are commonplace. Hearing loss in the elderly is considered normal and irremediable. Severe loss in children may be masked by behavioural disturbance and/or mental retardation (Denmark, 1978). In the traditional extended family associated with high infant mortality there appears to be a lower emotional investment by parents in any one child (unless he is an only son), and slowness to speak is less remarked than it would be in the small Western family. For the millions who have no school to attend and who engage in rural occupations, there is a lower demand for good hearing than there would be in the city.

At least three sorts of concealment commonly occur. The mother or other household member who first suspects deafness in an infant is likely to conceal her suspicions in the hope that the problem will resolve itself. Thus even when the possibility exists of detection and intervention during the crucial first twelve months, it rarely takes place. An older individual may conceal mild impairment by reading non-auditory cues and by avoiding situations requiring good hearing. When an impairment is noticed and considered serious, the family may conceal it in order not to prejudice the marriageability of close relatives and to avoid the stigma of disability, which in many areas is regarded as a punishment for parental sins (or for sins of the disabled person in a previous incarnation).

Attempts to remedy the hearing loss encounter the problem that it is not a serious 'felt need' of rural communities. Individuals may know that they or their children have impaired hearing, and want something done about it, but the community at large is not greatly moved by their predicament. People may or may not bother to speak up or turn towards the deaf person. Some sort of acoustic hearing aid may be fashioned or acquired, but modern amplification devices are unlikely to be available. If modern aids are obtained from the city, with difficulty and expense, they soon run into problems from tropical climate and unsophisticated users. Throughout the developing world spares and servicing facilities are practically unavailable, batteries are short-lived and difficult to obtain, and so are custom ear moulds.

FC160898

Holborow (1981) estimates that there are 500,000 profoundly deaf children in the developing world, while Hammerman (1981) quotes "at least six million" as a conservative figure for all children suffering hearing impairment (of significant degree) in developing countries, plus many millions of adults. It is a reasonable supposition that the percentage of prelingually deaf children is higher in developing countries than in the West. Post-natal influences include the low general level of hygiene, poor resistance to disease as a result of malnutrition, and high rates of respiratory disease, meningitis and other acute infections all of which increase the risk level. Perinatal factors include poor obstetric care and failure to give adequate treatment for neonatal jaundice and for rhesus incompatibility. Congenital conditions may be encouraged by the cloak of silence around venereal diseases and by the practice, common in many Asian communities, of first-cousin intermarriage. Being tied to poor general health and socio-economic conditions, conductive disorders probably also have a similarly high relative prevalence in the developing countries. Reducing infant mortality without tackling the causal factors will increase the prevalence of deafness, as will increasing life expectancy among older people.

To summarise the current circumstances of deafness in rural Asia: it is largely invisible; when recognised it is often not thought significant; if thought significant it may be concealed; if treatment is looked for it is usually unavailable or ineffective. As a target for community action it has low priority.

PERMISSION TO REPRODUCE THIS
MATERIAL HAS BEEN GRANTED BY

M. Miles

Attempted Solutions

The Western model to relieve the problem consists of

- 1) Preventive measures; 2) Early detection and intervention; 3) Specialised education where required; 4) Steps to encourage the integration of the hearing impaired into the normal life of the community.

Prevention of deafness incidentally by raising general health and hygiene standards, by immunisation schemes and by training traditional birth attendants already forms part of the health policy of many third world Governments. Specific measures such as educating communities away from consanguineous marriages, limiting drug usage during pregnancy, reducing noise levels in factories and public transport, requiring issue of hearing protectors for those at risk in industrial, military or entertainment occupations, are obviously difficult and may be unpopular. They are worth beginning nevertheless: the cost is not large, the propaganda effect is cumulative, and in the long run some deafness will be prevented by these means. Many safety rules are virtually unenforceable, but it may be possible to frame them in such a way that compliance becomes the easier option.

Money spent on prevention, however, wins no votes for politicians, especially if their opponents make preventive measures appear as interference with individual liberty. Furthermore the effectiveness of preventive measures will not become apparent (nor bring any political credit) until epidemiological capabilities have advanced a good deal further than at present in Asia. For many years to come there is going to be a great deal of unprevented hearing impairment. (Even among the comparatively well educated English, Nolan and Tucker (1981) report that almost one third of all sensorineurally deaf children seen in their Department have been deafened by rubella, due to poor take-up by teenage girls of freely available inoculation).

Early detection and intervention requires a) a viable community screening system; b) accurate testing centres with early childhood capability; c) appropriate hearing aids and maintenance facilities; d) community back-up to train and support parents in hearing aid monitoring and usage, and to practise in-home rehabilitative teaching. All four elements are required concurrently to make a significant impact. There is little point in early detection without intervention capability, or in testing centres without customers, or hearing aids without monitoring, maintenance and persistence in correct use.

In most of rural Asia none of these items is available. Modest efforts are being made to adapt and supply them in a few places. Week-long "hearing camps" have been conducted in rural areas by the All India Institute of Speech and Hearing, Mysore, with some success at least in the first three requirements. A recent eye-witness reports "en-masse screening for speech and hearing defects including basic ENT examinations, audiometry, prescribing of hearing aids, psychological tests for screening out the mentally retarded, on-the-spot essentials of speech therapy lessons to parents of children with defects, counselling for further steps and a good follow-up at the central Institute in Mysore ... 600/700 cases per day on average examination of patients at about 2 U.S. dollars per dozen." (Haggard, 1982)

On a less centralised and sophisticated level, CHILD-to-Child material has been used for hearing screening in rural Mexico, with older children using word and sound discrimination games to detect mild or moderate losses in young children. Attempts are being made to adapt and utilise the amplification capacity of the ubiquitous transistor radio as a substitute hearing aid. Home rehabilitation of the hearing impaired child is sketched briefly in the W.H.O. manual "Training the disabled in the community" (Helander et al, 1980), which is being used experimentally in a number of developing countries. The manual also describes ways of integrating hearing impaired persons into the normal life of the community, encourages the sending of all types of disabled children to normal schools, and illustrates some elementary types of sign language where normal communication is not feasible.

The Western approach tends to assume that normal medical care will have been carried out as a matter of course, but that will hardly be the case in much of rural Asia for lack of basic health awareness and personnel. Ear 'first aid' and medication is described in primary health care manuals by Werner (1977 edn.) and by King (1978), the latter profusely illustrating techniques such as dry-swabbing, syringing and removal of foreign bodies using a paper clip bent into a hook. This sort of basic information may do much to reduce the mild and moderate impairments caused by middle-ear infections. It may also reduce the amount of damage caused by traditional remedies such as the introduction of oil into the ear, poking about with long feathers or bodkins, and snipping beneath the tongue of the child who is not speaking.

More attention is currently being paid to vision screening in hearing impaired children (D.H.S.S. 1981). This is of particular importance in rural Asia, since the hearing impaired person needs to derive more information visually, while being more prone than average to suffering visual defects. Low-cost spectacles are much easier to supply and maintain than hearing aids. The testing (and re-testing in adolescence) of Down's syndrome children is also recommended where there is any hope of them having a better role than that of 'village idiot'.

Possible Improvements

The attempted solutions described above represent the early, uncoordinated efforts over ten or fifteen years since the problem of rural hearing impairment in developing countries began to receive attention at the international level. Most of the action has been 'imported', i.e. adapted by Western-trained professionals from Western models of prevention, treatment and rehabilitation, during a period when those models have themselves been evolving rapidly and painfully under the influence of new technology and changing attitudes towards disability. Incongruities may easily arise from the varied pace of development: while many parents in England still experience problems in obtaining well-fitting ear-moulds for high-power aids for their deaf children (D.H.S.S. 1981), a senior Asian professor reports to an ENT Conference that he is up to date with "the latest craze of the advanced countries" in being the proud possessor of the first acoustic impedance meter in the Sub-Continent.

The inability even in Britain to supply adequately an inexpensive but essential component of hearing aid services for children, and the Asian specialist's joy in the latest gadget, indicate areas where improvements may be possible and are urgently required, to relieve the problems of rural Asian deafness. These areas may be summarised as: 1) Information and Attitudes; 2) Associations; 3) Appropriate Technology.

1) Information and Attitudes The soundest basis for developing appropriate attitudes is accurate information in assimilable form repeated from different angles over a period of time, plus personal contact with the problem. (Miles, 1983). Aid organisations could provide much more help here, particularly in audio-visual presentations of appropriate intervention being practised in a third-world context, or in the West using Asian demonstrators. There are strategic student audiences in departments of medicine, public health, nursing, teaching, domestic science, social work and psychology, who are receptive to well-presented rehabilitation material. These are future trend leaders of developing countries.

Information is necessary also in the battle to wean specialists and teaching professors away from "expensive gadgets in disease palaces" and onto measures that will benefit a higher percentage of the population. The new Institute of Hearing in one third world capital is being equipped with Auditory Response Cradles (A.R.C.s). The provision in itself is neutral, but could be used in two very different ways: 1) As a prestige and publicity factor in a nationwide 'Hearing Alert' to sensitise parents and professionals to the need for the earliest possible detection and intervention with hearing impaired infants. (Only a small percentage of at-risk or suspected cases would in fact get to the A.R.C.s, but they could act as a symbol and backdrop for a big information and training effort based on simple distraction or cooperation tests.) 2) As merely one more fancy item on an inventory designed to impress visitors, from which a few senior specialists will squeeze 'research' papers. In either case, few babies will

benefit directly from the A.R.C.s; but the first way recognises the inevitable temptation to all but the poorest third world Governments to acquire the latest gadget, and turns it to a wider application. Western specialists participating in third world conferences could hasten this change of attitude, if they were themselves to perceive the necessity for a different or slower path of development.

Snags attached to the A.R.C. in its present stage of evolution illustrate the fallacy of hurrying to the latest 'technological fix', potentially brilliant though it may be, in the Asian situation. 1) The A.R.C. has been developed over the past 11 years and its use evaluated over 3 years or so (Bennett, 1981). As with most gadgets, the assessment of cost-effectiveness will lag behind the clinical tests. 2) It is a computerisation, using micro-processors, of a lengthy, skilled, human observation process, in order to provide a rapid, automatic screen for congenital deafness. If the human skill is down-valued it will cease to be propagated even in places with no prospect of acquiring the machine. 3) Parents will inevitably say later on that "He was tested at birth and found O.K.", dismissing later deafness from middle ear infection, trauma or progressive deterioration. (Bennett reports 13.5% failure to attend a follow-up clinic, among U.K. mothers). The A.R.C. at present uses high frequency inputs, and does not screen for low-frequency problems. Nor does it detect mild to moderate impairments. Furthermore it has been tested and evaluated on well babies, normal enough in the West but far from normal in rural Asia.

Attitude change is a key plank in the policy drawn up by Rehabilitation International (1980) and adopted by UNICEF, with an emphasis on seeing the disabled child not as a disease case but first as a child: in need of developmental stimuli as a normal child in all areas other than that of his disability, and then in addition needing special attention to his disability. There is more child than there is disability, yet too often the disability attracts disproportionate attention. The problem with this very worthy UNICEF emphasis is that it does not correspond to the perception of many rural parents. Having a mildly impaired child, they are likely to omit any attention to the disability; whereas with a severely impaired child their wish is entirely focussed on a cure for the disability. In either case, little impression will be made by talk of a long-running program of home rehabilitation and community integration.

2) Associations To engage in home rehabilitation, to acquire and disseminate appropriate information and to create better professional and community attitudes, are tasks beyond the unaided capacity of most individual parents or deaf adults in rural Asia. However there is strength in association, and it may be anticipated that much of the real development in rural areas in the next decade will arise from this source. In association, parents of hearing impaired children discover mutual needs, encouragement and resources. (Not all rural Asians are poor. Deafness may strike in the family of the landowner as well as the tenant and the landless labourer; the common need does something to bridge social barriers). Associations can press for Government aid, for genetic counselling, for provision of an itinerant hearing-aid technician, and other modest measures, with greater likelihood of success than an individual can.

Involvement of severely impaired deaf persons themselves will not be easy, given the circumstances in which they have grown up and the lack of a uniform communication system (exacerbated by the multiplicity of languages and dialects in Asian countries). There are however a number of people with an impairment sufficient for them to want to help the next generation avoid it, while not being so severe as to make insuperable communication problems. Exposure to deaf adults is also strongly recommended by advocates of Total Communication methods of raising deaf children, and is likely to be beneficial for early parent-child communication when the parents are hearing and the child is prelingually severely impaired. (Arguments from the Oral/Manual debate need to be re-thought in the rural Asian context).

The balance between individually-perceived priorities on the part of parents of hearing impaired children, and broader community requirements, may best be achieved by cooperation of professionals with parent associations. (Victor (1981) underlines the need for this 'resource person' role in development of Indian parent associations, while Hammerman (1981) sees no other means of mobilising adequate energy: "It is only as specialists see themselves as catalysts to train and release the energies of others

in the community, including teachers, family members, nurses, clergy, all of those people whose lives and work focus upon children and their needs, that sufficient people power will be mobilised to improve the situation of those millions of children with hearing impairments who are now living throughout the developing world, neglected and apart."

Parent/professional collaboration is vital for the training of families to make the best use of hearing aids when they are available. The necessary stages of detection, assessment, medical treatment, hearing aid prescription, and preparation of integrated schooling may be vitiated by the absence of such training. It is essential both where infants are fitted (who cannot of themselves indicate the need for adjustment) and older children, who may be reluctant to make the necessary efforts to utilise their newly acquired hearing capacity. When battery supply is difficult there will be a tendency to save batteries by part-time use. Freeman (1981) lists eight common reasons why deaf children in Canada do not use their aids, varying from poor fit, skin irritation and poor adjustment, to cosmetic problems and embarrassment. There is good reason to expect that quite as many problems will be encountered among rural Asian users.

3) Appropriate Technology The ideal hearing aid for rural Asia would be virtually indestructible, impervious to heat and humidity, need minimal monitoring and be within the capacity of a small-town radio technician to service, would use long-life batteries either of a common variety or solar rechargeable, would be small, light, easily attached to a child's head or clothing, and would cost less than 30 dollars. If such an item were needed for space exploration or military purposes, no doubt the specification would be met, apart from the cost. Such a miracle (or a near-miracle compromise) has yet to be produced by Western manufacturers.

Part of the problem has been in engineering difficulty, and part in the fact that the potential market has not been apparent. Rural Asia may better look to the Japanese, relative latecomers in the hearing aid field, whose attention to customer requirements and after-sales service in other fields has given them a strong marketing advantage. In the meantime, production within Asian countries of the most appropriate simple general purpose designs will go some way towards reducing costs and increasing local expertise. Added to this should be further experiment with single stage processes of ear mould manufacture, again to achieve a compromise between cost, user comfort, speed of delivery, durability, and the capabilities of the technicians or health personnel most likely to be making moulds.

Ten years is the minimum probable lag between electronics laboratory and village general store, for advances in hearing technology intended for rural Asia. During that decade some acoustic devices might be developed much more rapidly, for users with mild or moderate hearing loss. Niemoeller (1978) reports a gain of 10 to 20 dB over much of the speech frequency range. Grover (1977) commenting upon a similar range of gains from ear trumpet, auricles and conversation tube, points out that on this basis acoustic aids may be suitable for losses up to about 50 dB, since the gain actually used is commonly about half the measured hearing loss. The need would be to improve the convenience and visual effect of acoustic aids, within the available materials, cost and rural crafting ability.

Conclusion

In the short term, prospects are not very bright. The severely impaired can expect a grossly deprived and traumatic childhood; the mild and moderate will be labelled 'stupid', 'dumb' or 'difficult'; the elderly deaf person will progressively become isolated. Preventive measures and appropriate technology will have some effect over a period of years. In the meantime the need is to utilise latent community resources by mobilising deaf persons and their families, providing accurate, appropriate information on deafness and rehabilitative measures, and changing professional attitudes towards a community orientation.

Acknowledgement

I am indebted to Professor M.P. Haggard, Mr. C. Holborow, Mr. D.C.M. Dale, Mr. G. Helsingrove and Mrs. S. Hammerman, for their supply of documents, comment and encouragement.

References

- Bennett, M.J., and Wade, H.K. (1981) *Hearing Aid Journal*, 34, 11
- Denmark, J.C. (1973) *Brit. J. Mental Subnormality*, 24, 81-89
- D.H.S.S. (1975) *Advisory Committee on Services for Hearing Impaired People (Sub committee on rehabilitation of adults) Report*
- D.H.S.S. (1981) *Advisory Committee on Services for Hearing Impaired People (Sub committee in services for children) Final Report*
- Freeman, R.D., Carbin, C.F., Boese, R.J. (1981) *Can't Your Child Hear ?* Croom Helm, London
- Grover, B.C., (1977) *A Note on acoustic hearing aids*, *Brit. J. Audiol.* II, 1977
- Haggard S.D. (1982) *Personal communication*
- Hammerman, S. (1981) *Assignment Children* 53/54, UNICEF, Geneva
- Helander, F., Mendis, P., Nelson, G. (1980) *Training the disabled in the community.* W.H.O., Geneva
- Holborow, C., Martinson, F., Anger, N., (1981) *A study of deafness in W. Africa*, Commonwealth Society for the Deaf, London
- King, M., King, F., Martodipoero, S., (1973) *Primary Child Care*, OUP Oxford
- Miles, M. (1983) *Public Attitudes towards Disabilities.* (In preparation) National Council of Social Welfare, Government of Pakistan
- Nolan, M., and Tucker, I. (1981) *The Hearing Impaired Child and the Family.* Souvenir Press, London
- Rehabilitation International (1980) *Childhood disability : its prevention and rehabilitation.* UNICEF, New York
- Victor, P. (1981) *Prospects* XI, 4, UNESCO Paris
- Werner, D., (1977) *Where There is no Doctor.* Hesperian Foundation, USA

Peshawar Jan. 1983

M. Miles